Evaluation of symptom severity and life quality of cancer patients in palliative care unit

Symptom Severity, Life Quality, Palliative Care Unit

Zülfünaz Özer[1], Rukiye Pınar Bölüktaş[1], Ayşe Nefise Bahçecik[1], Gülistan Şakar[2]
[1]Department of Nursing, Faculty of Health Sciences, Istanbul Sabahattin Zaim University,
[2]Beylikdüzü State Hospital, Istanbul, Turkey

Abstract

Aim: This cross-sectional and descriptive study was conducted to evaluate the symptom severity and quality of life levels of cancer patients hospitalized in palliative care units, and the effect of symptom severity on quality of life.

Material and Methods: This study included 100 cancer patients hospitalized in palliative care units between November and December 2019, who accepted to participate in the study. Data were collected through face-to-face interview and Patient Information Form, Edmonton Symptom Assessment Scale (ESAS) and Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale through face-to-face interview.

Results: The mean age of the participants was 66.4 years; 51% were females and 77% of the patients received care help from their spouses. Lung cancer was diagnosed in 30% of the patients, 98% were at the fourth stage of the disease, and 66% received chemotherapy. Most severely experienced symptoms were as follows in order: lack of appetite, dyspnea, fatigue, changes in skin and nails, anxiety, pain, and drowsiness. Life quality mean scores were 9.5±3.06 for physical well-being, 12.5±4.41 for social life/family well-being, 8.9±3.19 for emotional well-being, 4.8±3.08 for functional well-being, 29.7±8.09 for other concerns, and 65.3±14.50 for total FACIT-Pal.

Discussion: It was determined that the patients had high symptom severity and low life quality; besides as the severity of the symptoms increase, life quality decreased.

Keywords

Palliative care; Life quality; Symptom severity

Introduction

Palliative care is an approach that increases the life quality of a patient, together with and his/her family, who has experienced a life-threatening serious disease, by early diagnosis, evaluation and treatment of physical (primarily pain), psychosocial and spiritual problems. WHO declares that patients with cancer, cardiovascular diseases, chronic respiratory diseases, and chronic renal failure require palliative care [1]. Cancer patients in palliative care units are reported to experience many physiological and psychological symptoms like pain, fatigue, asthenia, respiratory distress, nausea, vomiting, mucositis, constipation, lack of appetite, weight loss, anxiety, and depression [2,3]. It is also determined that problems experienced due to these symptoms negatively affect the functionality and life quality of patients [2-4].

Life quality is defined as how individuals perceive themselves concerning expectations from life, purposes, interests, and standards within the context of their own culture and values. Many factors like physical, psychological status and performance of the individual, relationship with family members, environmental events, belief status, chronic terminal diseases, and the support level affect the life quality of an individual [5]. The symptoms of palliative care patients with life-threatening chronic diseases (pain, dyspnea, anxiety, nausea, vomiting, etc.) have a particularly negative effect on the life quality of individuals [2].

The purpose of palliative care is to improve functional capacity and relieve pain and improve life quality by controlling the symptoms while acting responsibly for the cultural and local values, beliefs, and applications of the beliefs of individuals [1]. It has been reported that usually attention is focused on the management of a single symptom in cancer patients experiencing multiple symptoms [3]. When focusing on only one symptom, other symptoms may escape attention, treatment falls short and this negatively affects the life quality of the patient [6]. When the disease and symptoms arising from therapy are not brought under control, patients may give up therapy, the dosage of therapy may have to be reduced or the therapy may be discontinued. Controlling the symptoms is crucial for the patient and family in coping with the therapy [7,8]. Systematic evaluation of all the symptoms of the patient would provide information on disease prognosis and would help in clinical decisions on how to increase the life quality of the patient [9].

Systematic and regular evaluation of symptoms is important for effective symptom management and maintaining and sustaining the life quality of the patients [2]. Nurses must define the symptoms of their patients through comprehensive symptom evaluation and evaluate the life quality of their patients in palliative care. Patients should receive holistic care according to symptom management and their life quality should be improved [6,10,11]. Besides, correct measurement of patient's life quality is necessary for evaluation of service provision and testing the efficacy of the intervention [12]. In light of this information, this cross-sectional and descriptive study was conducted to evaluate the symptom severity and quality of life levels of cancer patients hospitalized in palliative care units and the effect of symptom severity on quality of life.

Material and Methods

Study type

This study is a cross-sectional descriptive study.

Universe and Sample of the Study

This study was done between November and December 2019, in the palliative care units of three hospitals in Istanbul. The universe of the study was composed of 120 patients hospitalized in these hospitals during the indicated period. The sample of the study included 100 patients that were over 18 years of age, conscious, able to communicate verbally, and accepted to participate in the study.

Data Collection Tools

Research data were collected through face-to-face interviews with the patients. Data were collected using the "Patient Information Form", "Edmonton Symptom Assessment Scale (ESAS)" and "Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal) Scale".

Patient Information Form: This form was developed by the researchers and included questions about patients' age, gender, marital status, whether they had children, education status, spouse, employment status, unemployment reason, income, the person responsible for the care, diagnosis, metastasis status, chemotherapy status, radiotherapy status, surgical therapy status, other chronic disease status and the stage of the disease.

Edmonton Symptom Assessment Scale (ESAS)

Edmonton Symptom Assessment Scale (ESAS) evaluates the symptoms like pain, fatigue, nausea, sadness, anxiety, drowsiness, lack of appetite, feeling unwell, dyspnea, changes in skin and nails, mouth sores, and paresthesia in hands, which are commonly observed in cancer patients, with a score between 0 and 10. Zero indicates no symptom, while 10 indicates a very severe symptom. This scale was developed by Bruera et.al. (1991) and the validity and reliability of the Turkish version of the scale were done by Sadırlı and Ünsar (2009). Chronbach's alpha value for the scale was calculated as 0.76 [14]. In this study, Chronbach's alpha value of the scale was found as 0.79.

Functional Assessment of Chronic Illness Therapy- Palliative Care (FACIT-Pal) Scale

Functional Assessment of Chronic Illness Therapy- Palliative Care (FACIT-Pal) Scale is one of the life quality scales of Functional Assessment of Chronic Illness Therapy (FACIT) Measurement System that is widely used in clinical research. The validity and reliability of the Turkish version of the scale was done by Bagcivan et.al. (2019). This scale is used to evaluate the life quality associated with palliative care. The scale is composed of 45 items (26 items for FACIT-G and 19 newly added items on additional concerns/palliative care) with 5- point Likert type questions (0: None-4: Very Much). FACIT-Pal (0-180 point) is composed of five subscales: physical well-being (0-28 points), social/family well-being (0-24 points), emotional well-being (0-24 points), functional well-being (0-28 points) and additional concerns (0-76 points). Higher scores from subscales and total scale indicate higher life quality. Chronbach's alpha value for FACIT-Pal total scale is 0.93 and Chronbach's alpha values calculated for subscales are between 0.73 and 0.86 [15]. In this study, Chronbach's alpha value was calculated as 0.82 for the total FACIT-Pal scale, and it was found to be between 0.70 and 0.75 for subscales.

Data Evaluation

SPSS version 25.00 statistical package program was used for data analysis. Percentage, mean, standard deviation, and multiple regression analysis were used for descriptive statistics. The significance level was accepted as p<0.05.

Ethical Aspects of The Study

The approval (31.07.2019 date and 2019/07 numbered) was obtained from the Directorate of the Ethics Committee of one university. Oral consent was obtained from patients included in the study, after informing them about the aim and application method of the study. This study was done following the ethical standards of the Helsinki Declaration. Voluntary participants were included in the study and personal identifying information was kept confidential.

Results

The mean age of the patients was 66.43±10.14 years; 51% were female, 87% were married, 88% had children, 58% were primary school graduates, 56% lived with their spouse and children, 99% did not work, 58% were retired and 67% had moderate-income (Table 1). Among the patients, 35% had no other chronic diseases, and spouses provided care for 77%. Lung cancer was diagnosed in 30% of the patients, 37% had metastasis, 66% received chemotherapy, 10% received radiotherapy, 4% received surgical therapy; almost all of the patients (98%) were at stage 4 (Table 1).

The severity of patients' symptoms is presented in Table 2.

Table 2. Symptom severity distribution in patients according to ESAS (N= 100)

Symptoms	Mean± SD	Min-Max
Pain	7.40±2.30	0-10
Fatigue	7.70±2.27	1.Eki
Nausea	6.20±2.48	1.Eki
Sadness	7.24±2.22	0-10
Anxiety	7.40±1.94	0-10
Lack of sleep	5.95±2.95	0-10
Lack of appetite	8.00±1.86	0-10
Feeling unwell	7.30±1.98	1.Eki
Dyspnea	7.80±1.53	2.Eki
Changes in skin and nails	7.30±2.08	0-10
Mouth sore	5.63±2.92	0-10
Paresthesia in hands	5.22±2.73	0-10

The most severe symptoms were as follows in order: lack of appetite (8.0±1.86), dyspnea (7.8±1.53), fatigue (7.7±2.27), anxiety (7.40±1.94), pain (7.40±2.30), changes in skin and nails (7.30±2.08), feeling unwell (7.30±1.98), sadness (7.24±2.22) and nausea (6.20±2.48).

Life Quality scores of patients were 9.5±3.06 for physical well-being, 12.5±4.41 for social/family well-being, 8.9±3.19 for emotional well-being, 4.8±3.08 for functional well-being, 29.7±8.09 for additional concerns, and 65.3±14.50 for total FACIT-Pal.

Table 1. Distribution of patients according to their introductory information and some characteristics of their diseases (n=100)

		Mean±SD		Min-Max (Median)		
Age		66.43±10.14		45-89 (66)		
		N	%		N	%
Gender	Female	51	51.0	Person responsible for care	Wife	77	77.0
	Male	49	49.0		Children	5	5.0
Marital Status	Married	87	87.0		Other Relatives	2	2.0
	Single	13	13.0		Professional Nursemaid	16	16.0
Children	Not present	12	12.0	Other chronic disease status	Not Present / Present	65 / 35	65.0 / 35.0
	Present	88	88.0		Gastric Cancer	14	14.0
Educational Status	Not literate	7	7.0		Colon Cancer	19	19.0
	Literate	3	3.0		Lung Cancer	30	30.0
	Primary School	58	58.0		Pancreas Cancer	9	9.0
	Secondary School	6	6.0	Diagnosis	Liver Cancer	4	4.0
	High School	21	21.0		Brain Tumor	5	5.0
	Undergraduate and above	5	5.0		Kidney Tumor	2	2.0
Lives with	Spouse and children	56	56.0		Breast Cancer	12	12.0
	Spouse	30	30.0		Tongue Cancer	1	1.0
	Nursemaid	11	11.0		Uterus Cancer	4	4.0
	Alone	3	3.0	Metastasis Status	Not Present / Present	63 / 37	63.0 / 37.0
Working Status	Working	1	1.0	Chemotherapy Status	Not Present / Present	66 / 34	66.0 / 34.0
	unemployed	99	99.0	Radiotherapy Status	Not Present / Present	Eki.90	10.0 / 90.0
Reason for not working	Retired	58	58.0	Surgical Therapy Status	Not Present / Present	Nis.96	4.0 / 96.0
	Quit because of the disease	10	10.0	Disease Stage	Not Present / Present	Şub.98	2.0 / 98.0
	Housewife	32	32.0				
Income	High	30	30				
	Moderate	67	67.0				
	Low	3	3.0				

Table 3. Multiple Linear Regression analysis findings on FACIT-Pal prediction of symptoms

Model	Variables	B	S. Error	β	t	p
1	Constant	115.239	6.607		17.442	0.001**
	Nausea	-2.07	0.503	-0.348	-4.115	0.001**
	Sadness	-3.659	1.096	-0.552	-3.338	0.001**
	Anxiety	Şub.81	Oca.25	-0.371	2.249	0.027*
	Feeling Unwell	-2.221	0.575	-0.299	-3.864	0.001**
	Dyspnea	-1.677	0.746	-0.175	-2.249	0.027*

R=0.726, R^2=0.527

$F_{(5,94)}$=20.961, p=0.001*

FACIT-Pal: Functional Assessment of Chronic Illness Therapy- Palliative Care, *p<0.05
**p<0.01

When Table 3 was evaluated, multiple linear regression analysis done to determine the effect of independent variables on FACIT-Pal turned out to be statistically significant (F(5.94)=20.961, p<0.001). Independent variables in the model accounted for 52.7% of the total variance in FACT-Pal (R2=0.527, p<0.001). When regression coefficients were analyzed, it was found that nausea β=-0.348, p<0.001), sadness (β=-0.552, p<0.001), anxiety (β=-0.371, p<0.001), feeling unwell (β=-0.299, p<0.001) and dyspnea (β=-0.175, p<0.001) variables had a negative and significant effect on FACIT-Pal.

Discussion

Physical, psychosocial, and spiritual symptoms, experienced by palliative care patients, restraint their lives, result in the feeling of loss of control over life, and negatively affect their life quality [3]. This study was conducted to evaluate the symptom severity and quality of life levels of cancer patients hospitalized in palliative care units and the effect of symptom severity on quality of life. The findings of this study are discussed according to the literature.

The most severe symptoms of patients are lack of appetite, dyspnea, fatigue, anxiety, pain, changes in skin and nails, feeling unwell, sadness and nausea, in the order of severity. Saygılı and Çelik (2020) reported that patients in palliative care units experienced fatigue, feeling unwell, lack of appetite, anxiety, sadness, and pain symptoms most frequently. Various studies also determined palliative care patients experience fatigue, lack of appetite, feeling unwell symptoms [17]. Omran et.al. (2017) stated the most frequent symptoms of patients as lack of energy, pain, mouth dryness, lack of appetite, drowsiness, and dyspnea. Another study on palliative care patients determined the most commonly experienced symptoms, including pain, fatigue, dyspnea, nausea, and cough [3]. A review on the subject listed the most frequent symptoms as pain, dyspnea, fatigue, lack of appetite, nausea, and vomiting, constipation, anxiety, and depression [7]. Radiotherapy receiving palliative care patients were reported to experience fatigue, drowsiness, feeling unwell, pain, nausea, lack of appetite, and dyspnea most frequently [9]. The findings of our study reveal a different ranking of symptom frequency, compared to the literature. A possible reason for this difference could be the inclusion of different patient groups.

It has also been stated that symptom experience is dynamic and therefore results in different symptoms being experienced among patients [2].

In this study, patients' physical well-being, emotional well-being, functional well-being states, additional concerns, and FACIT-Pal total life quality scores were found to be low. A study on palliative patients also found low physical and emotional functionality and total life quality score [18]. Another study on palliative patients determined the life quality of the patients (including physical functionality, role functioning, emotional functionality, cognitive functionality, and social functionality subscales) was low [19]. A systemic review on the life quality of palliative care patients also determined a low life quality score [20]. Another study by Soares Cruz (2019) also found low life quality among patients [21]. There are various studies in the literature reporting low life quality scores among palliative care patients [2,11,22]. Our findings are consistent with the literature, pointing out that the physical, functional, and emotional losses of palliative care patients affect life quality negatively.

Patients' sadness, nausea, anxiety, feeling unwell and dyspnea symptoms are the variables that negatively affect life quality, in our study. Bužgová and Sikorová (2015) reported pain, dyspnea, lack of sleep, and lack of appetite as symptoms negatively affecting life quality and stated that life qualities of palliative care patients were related to good symptom management and high-quality nursing care [19]. A meta-analysis by Kassianos et al. (2018) stated that improvement in pain, nausea, fatigue symptoms affected life quality positively [23]. It has also been found that as the severity of fatigue, lack of appetite, and feeling unwell symptoms increased, life quality was negatively affected [11]. Emotional problems and fatigue-pain symptoms were stated to negatively affect the life quality and general health of patients [24]. Also, physical, gastrointestinal, respiratory, and psychological symptoms experienced by patients negatively affected life quality [2]. Our findings were similar to those in the literature. Symptom severity of patients negatively affected life quality. Symptoms of patients must be periodically evaluated and controlled to improve life quality.

Limitations of the Study

This study has several limitations. First, the findings of this study are valid for the patients included in the study; therefore, it cannot be generalized to all palliative patients. Second, the reliability of the data is limited by the trueness of the answers of patients who participated in the study.

Conclusion

It was determined that the patients had high symptom severity and low life quality; an increase in symptom severity (sadness, nausea, anxiety, feeling unwell, and dyspnea) decreased life quality. Each symptom of palliative care patients must be addressed separately and evaluated periodically. It is suggested that life quality should be evaluated from all aspects, and the life quality of patients at the last stage of their disease should be improved with appropriate interventions. The presence of other potential variables decreasing the life quality of palliative care patients should also be investigated.

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